

Meeting Attendees	
Name	Organization
Margaret Donnelly (Co-Chair)	Missouri Department of Health and Senior Services
Scott Lakin (Co-Chair)	Lakin Consulting
Mary Becker	Missouri Hospital Association
Brian Colby	Missouri Health Alliance
Arthur J. Culbert, PhD	Missouri Foundation for Health
Carol Hafley	Missouri Center for Patient Safety
Jeffrey Howell, J.D.	Missouri State Medical Association
Joy Jacobsen	CareEntrust
Lynn Konstant	Missouri Department of Health and Senior Services
Jessica Land	Patek & Assoc.
Jean Leonatti	Central MO Area Agency on Aging
Barb Oerly	Infocrossing
Drew Oestreich	Pharmacy Agent Corporation
Joe Palm	Department of Health and Senior Services
Brian Roy	Availity, LLC
Ed Tasch	NCADA – St. Louis
Staff	
Charlotte Krebs	Primaris
Melinda Dutton	Manatt Health Solutions
Kier Wallis	Manatt Health Solutions

Next Meeting	January 12, 8:30 am – 11:30 am CT Location TBD
Action Items	<p><i>The Consumer Engagement Workgroup will meet bi-weekly. In-person attendance is strongly recommended.</i></p> <p><i>Please contact Workgroup staff (contact information below) with questions about the Workgroup framework, process, or timeline.</i></p> <ul style="list-style-type: none"> ➤ Compile and share information/products/articles produced by consumer engagement initiatives. ➤ Compile and share information around consumers' abilities to review and comment/request changes to inaccurate information in their records; what is the process to correct inaccuracies in a medical record? ➤ Workgroup members will be notified when draft strategic plan content is available for review ➤ Workgroup participants to provide feedback to kwallis@manatt.com by January 4, 2010. Alternatively, Workgroup can submit feedback through survey on State website: dss.missouri.gov/hie. ➤ Workgroup participants to send suggestions of additional stakeholders to ckrebs@primaris.org.

<p>Content Reviewed</p> <p><i>Materials are available online at: dss.missouri.gov/hie</i></p>	<ul style="list-style-type: none"> ➤ Consumer engagement principles in health information technology (IT) and health information exchange (HIE) initiatives <ul style="list-style-type: none"> ○ Transparency ○ Consumer access ○ Confidentiality and informed consent ○ Data integrity and security safeguards ○ Oversight and enforcement ➤ Examples of national models and state-based initiatives <ul style="list-style-type: none"> ○ Markle Foundation: Connecting for Health ○ Consumer Partnership for eHealth ○ New York eHealth Collaborative (NYeC) Consumer Advisory Council ➤ Draft key principles for consumer engagement in Missouri <ul style="list-style-type: none"> ○ Transparency of policies and practices relating to HIT/HIE ○ Consumer access to health IT tools and health information ○ Confidentiality and informed consent in use of health information ○ Data integrity and security safeguards for health information ○ Oversight and enforcement of remedies for any security breaches or privacy violations ○ Outreach and education efforts to proactively engage consumers ➤ Consumer engagement strategy <ul style="list-style-type: none"> ○ Stakeholder feedback via web survey and emailed comments ○ Other state strategies for consumer engagement: Environmental scan and evaluation; capacity building; consumer outreach and education ○ Consumer engagement activities in Missouri that may be leveraged
<p>Key Commentary & Discussion</p>	<p>Principles</p> <ul style="list-style-type: none"> ➤ Consumer engagement principles should reflect the spirit and mission of HIE and must be written for the general public's consumption <ul style="list-style-type: none"> ○ Medical information shared with consumers should be at an appropriate reading level and tailored for public consumption ➤ If HIE is robust and works well, an electronically-based system will be much better than the current paper system, but it won't be perfect; physicians will still have to work under the assumption that consumers may not share complete information ➤ Principles are not listed in a specific order; the order of principles may be discussed at a future meeting. ➤ What do we know about consumer response to HIE and uptake in other states? <ul style="list-style-type: none"> ○ This is a nascent field; there is not a lot of information publicly available ○ In initiatives where a consumer has to affirmatively opt-in there have been high opt-in rates reported; these initiatives are typically accompanied by educational and communication campaigns ○ Tennessee is starting to conduct a consumer poll. ○ New York created a speakers bureau and worked with consumer advocacy groups to gauge consumers responses. ○ Where consumers are educated about the benefit, have had high participation rates. ○ Outreach has been a critical component to success ○ Massachusetts eHealth Collaborative requires affirmative opt-in consent and has had a positive response ○ It has been shown that consumers who initially opt out typically opt in after gathering information. ➤ Revisions to principles

- Emphasize the values of affordability, quality, safety, and efficiency
- Principles should acknowledge potential issues, but not address individually (e.g. substance abuse, mental health, proxy, minor, immigrant and minority health).
- Refine second principle "Consumer access to health IT tools and health information" to state "There are some individuals who will need to designate a proxy, such as..."
- Refine "Outreach and education efforts to proactively engage consumers" to include special populations.
- New principle: These initiatives should be focused on maximizing the value and improving the quality and safety of care, and improving the public's health.
- Augment "Confidentiality and informed consent in use of health information" to specify that consumers should know how their information is used.
- Recognition of the patient's right to review and comment on their records; consumers do not have the ability to change the content of their health records, but they may be able to "append" notes.
 - Consumers should have access to review the content of their records
 - The Workgroup would like to understand how this is being handled in other states.
- New principle: Consumer engagement should be ongoing and not finite in the current process.
- Non-English speaking residents may be suspect of sharing information; outreach materials and campaigns must address language barriers.
- There is tremendous value in aggregated public health information, but caution must be taken to ensure protection of patient identity and trust.
 - The business community would appreciate a greater level of transparency around aggregated data
- Some populations may have outstanding trust issues that will need to be addressed.
- Designating a proxy to access information or help with care decisions is as important for the aging population as for the minor population
- There are special situations and issues that arise with access to children's records
- There must be an established level of trust among consumers to facilitate consumer uses and access to information. In the current paper system consumers may choose not to share information and physicians must make decisions without complete information; this will be repeated with electronic records.

Consumer Engagement Strategy Discussion

- For purposes of evaluation a third party evaluator should be engaged
- HIE rollout may be analogous to Medicare Part D rollout; lessons and strategies from the Medicare Part D rollout may be leveraged.
 - During the rollout it was effective to sit one on one with individuals in front of the computer and walk through the process.
 - Public libraries and senior centers were effective locations for communication
- There may be a role for philanthropic/trusted organizations to play
- Efforts should be coordinated with the Regional Center so that provider

	<p>education trickles down to consumers</p> <ul style="list-style-type: none"> ➤ Potential tactics <ul style="list-style-type: none"> ○ Create and launch short (3 or 4 minute) videos that explain “how it works” ○ Educate consumers about evidence-based medicine and its purpose/relationship to health information exchange ○ Engage the faith-based community. Faith-based communities are strong in rural areas; they also typically lack sophisticated technologies. ○ FQHCs should be engaged as points of communication/ dissemination ➤ How do we prioritize among consumer engagement activities? What should the products be? <ul style="list-style-type: none"> ○ Health literacy and addressing language barriers should be a priority ○ Launch a website with communication materials akin to a press kit – frequently asked questions; inventory of consumer resources; patient rights and privacy tips ○ The Health Information Security and Privacy Collaborative (HISPC) may have some materials that may be leveraged. ○ Consumer awareness forum and town hall meetings will be important to gather input from target populations. ○ Focus groups or polling may provide baseline knowledge; polling may be more appropriate initially, followed by focus groups to review specific messages and products. ➤ Who or what organizations are experienced in consumer outreach? Who will implement these efforts? <ul style="list-style-type: none"> ○ Missouri Foundation for Health – Health Literacy Project and Reach Healthcare Foundation are experienced in consumer outreach ○ It will be part of the HIE governance entity's role to set policy for HIE in Missouri and support consumer outreach and engagement; efforts should be geographically and ethnically diverse to represent the state. <ul style="list-style-type: none"> ▪ <i>As part of the governance structure, there should be a person tasked with consumer engagement; there may also be a Consumer Advisory Group to the governance entity.</i>
<p>Key Decisions</p>	<ul style="list-style-type: none"> ➤ Suggested revisions and additions to principles <ul style="list-style-type: none"> ○ Refine principle “Consumer access to health IT tools and health information” to state “There are some individuals who will need to designate a proxy, such as...” ○ Refine “Outreach and education efforts to proactively engage consumers” to include special populations. ○ Augment “Confidentiality and informed consent in use of health information” to specify that consumers should know how their information is used. ○ Additional principles <ul style="list-style-type: none"> ▪ These initiatives should be focused on maximizing the value and improving the quality and safety of care, and improving the public's health. ▪ Consumer engagement should be ongoing and not finite in the current process. ➤ The Workgroup recommended that as part of the HIE governance structure there should be a person tasked with consumer engagement; the

Next Meeting	governance organization should support the implementation of consumer outreach and engagement.
	<ul style="list-style-type: none">➤ Review and discuss draft content for strategic plan – draft will be circulated in advance➤ Continue discussion of consumer engagement strategy and principles.
Workgroup Staff Contact Information	<ul style="list-style-type: none">➤ Charlotte Krebs – ckrebs@primaris.org➤ Melinda Dutton – mdutton@manatt.com➤ Kier Wallis – kwallis@manatt.com➤ Alice Lam – alam@manatt.com